

CASE EXAMPLES – CONSUMER DIRECTED COMMUNITY SUPPORT WAIVERED SERVICE

Consumer Directed Community Support was added as a MR/RC waived service option in early 1998 in conjunction with Minnesota's Self Determination Project.

MATTHEW

Matthew is an active, engaging six-year-old boy with severe autism. By the time Matthew was four years old, his family had exhausted all of their personal financial resources, including a second mortgage on their home, to implement a specific intervention method. They needed to use their own financial resources because the method, though very effective with their son, was not one agencies and their staff were willing or able to implement. When hearing about the opportunity to access the Consumer Directed Community Support (CDCS) option, Matthew's parents jumped at the opportunity. By managing their resources themselves, they have been able to recruit, select and train the staff that provide Matthew's intervention. They are able to arrange for staff to be trained by intervention experts. Because they have been able to divert resources to staff that had formerly been part of an agency's overhead, the resources go further for Matthew. Matthew's parents have access to an organization that is the Employer of Record for the staff so that all relevant tax and employment responsibilities are met. They pay them for exactly what they are doing, and nothing more. Since being able to provide this intervention virtually full time, Matthew has acquired a myriad of new skills. He is talking and reading. He will attend regular kindergarten this fall. As his mother says, if we invest in him now, he has the potential to grow up to become a contributing member of his community.

ELYSE

Elyse is a young woman in her mid 30's. Previously she attended a formal day program full time. They had been unable to provide Elyse with the work schedule and support she desired. Using CDCS, she and her parents have diverted resources previously available only if she attended the day program, to pay a neighbor to provide some job support at a job she found. She still attends the day program two days a week to receive some occupational therapy and participate in community activities. With the inception of CDCS, services for Elyse are no longer "all or nothing". In addition, Elyse and her family are using some of the support funding to provide in-home support for Elyse, who still lives with her parents. Elyse's mother excitedly reported on one occasion how wonderful it is to be able to have control of Elyse's resources and support. She had run in to the woman who had provided day care to Elyse years before. The woman was willing and able to provide some support for Elyse. They were able to take immediate advantage of the situation through the use of CDCS.

DUSTIN

Dustin (names have been changed) is 2 years old. He was born with severe and multiple disabilities. He has had numerous surgeries and continues to have serious medical issues. When Dustin was born, both his parents had full time professional careers. Though authorized for 16 hours of service per day, staff were not available to fill the hours. Services that were provided were delivered by up to five different staff in a single week. Dustin's parents could not trust the care of their son to them. It soon became apparent that they could not care for Dustin and both continue in their careers. They decided that Dustin's father would put his financial planning career on hold for the time being, and remain home with Dustin. For the past year and a half, he has done so. Now, using the Consumer Support Grant, Dustin's parents were able to go outside the service system for support. Dustin's aunt was just planning to return to the work force part time, since her children are now in school all day. Dustin's parents have hired Dustin's aunt to come in to their home for 5 hours a day to care for Dustin. His father is able to return to his career on a part-time basis. She is also willing to stay overnight with Dustin from time to time so his parents can get a break from the constant demands of his care. They are also able to pay a neighbor, who cares for Daniel from time to time. His parents have confidence in the care his aunt will give and they know they can depend on her to be there.

HEATHER and LYNN

Linda is a single mother with two preteen daughters, Heather and Lynn. Both have significant behavioral challenges due to autism. Predictability and consistency of intervention are essential to their development. Between the two girls, they are authorized to receive 11 hours of PCA (Personal Care Attendant) services per day. They have been relying on an agency to cover the staff hours. Since September, they have received only 1.5 hours of service total. Linda is an MFIP participant who is nearing her five-year limit. Because the PCA service is inconsistent and unreliable, she has been unable to get and keep a job outside her home. Her plan, under the Consumer Support Grant Program, is to use a portion of the funds to pay herself, thereby meeting two objectives: her daughters have safe, stable, relation-ship-based care and she is gainfully employed. Other funds will be used to purchase support from a good friend of hers who knows her daughters well, and to whom she is willing to entrust their care. Her plan was developed within established guidelines and parameters with the assistance of their Dakota County social worker. It was approved at both the county and state levels. The social worker monitors implementation monthly for consistency with the approved plan. Linda reports significantly reduced stress and chaos in their home, as well as progress for her daughters.

Linda is not alone in her inability to maintain employment outside her home while caring for a child with disabilities. At a recent meeting for parents of children with disabilities, five out of the six women present had interrupted professional careers because the physical and medical demands of their children with disabilities could not be met when both parents were working. In other families in which both parents work, it is not unusual for them to strategically make a decision about which will risk losing their job due to absenteeism. It is usually the one who does not carry the health insurance.

PHILIP

Philip, a young man in his early 20's, has significant physical and cognitive disabilities. He uses a wheel chair, and communicates primarily through sounds and gestures. Those who do not know him well have difficulty understanding and responding to his needs. Since he was very young, his parents have worked opposite shifts so that one could always be home with him. Though most recently authorized for eight hours of PCA support a day, they had used none because they did not trust their son's care to staff the agency sent. With the Consumer Support Grant Program, Philip's mother has been able to quit her job, and be paid to provide support that the agency was unable to provide. The plan development, approval and monitoring process is the same as the one described above. Philip's parents report that he is doing well, and that for the first time in their memories, they are experiencing life together as a family.

EXAMPLES - CONSUMER SUPPORT GRANT AND CONSUMER DIRECTED COMMUNITY SUPPORT

OVERVIEW

People with disabilities and their families are faced with a severe crisis: agencies are not able to provide the staff to fill authorized hours of service. Service, when it is delivered, is inconsistent, sporadic and undependable. In reviewing services delivered by the traditional system for current Consumer Support Grant participants, they had received, on average, less than 25% of the services for which they had been authorized. Demographics say the situation will only become worse as the number of those requiring care – those with disabilities and the aging – grows, while the number of available caregivers – primarily women under the age of 35 – decreases. Alternatives to the traditional agency-provided services are imperative in order for those with disabilities to remain in their homes and communities.

Two examples of such alternatives are already available in Minnesota. One is the current Consumer Support Grant Program. The second is Consumer Directed Community Support, a service option under the MR/RC (mental retardation/related conditions) Waiver. These allow consumers, and their families/legal representatives to use support funds to hire from their own personal networks and other nontraditional sources, i.e., family members, neighbors, coworkers and friends. In Dakota County 25 families are taking advantage of the Consumer Support Grant Program. The number requesting the program is growing faster than the capacity to respond. The same is true for the Consumer Directed Community Support option of the MR/RC Waiver which is currently used by over 50 consumers and families.

The vast majority of those using the Consumer Support Grant are families with minor children with disabilities. The rest are families with adult children with disabilities living in their family homes. Of those families with minor children, all but four are eligible for Medical Assistance because of TEFRA. Their fees range from \$25.00 to several hundred dollars per month. Approximately one-third of those using Consumer Directed Community Support are minor children living with their parents. The rest are adults. While the majority of the adults live with their parents, several are in foster care or other supported living arrangements.

CASE EXAMPLES – CONSUMER SUPPORT GRANT PROGRAM

The current Consumer Support Grant Program enables consumers to have direct access to and control of up to 47%, the state share, of their Medical Assistance Home Health Care authorization. Many consumers and families are willing to take access to less funds in exchange for consistent quality care. However, for some, the needs are so high that 47% would not be sufficient; they need access to the Federal portion of the funds as well. Following are examples of two situations in which consumers/families have chosen to participate in the existing program.